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## Daily functioning in children with developmental coordination disorder

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*Document Version*

Publisher's PDF, also known as Version of record

*Publication date:*

2014

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

van der Linde, B. (2014). *Daily functioning in children with developmental coordination disorder: Assessment of activities of daily functioning*. [Thesis fully internal (DIV), University of Groningen]. [S.n.].

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# CHAPTER I

## GENERAL INTRODUCTION

## INTRODUCTION

Children with developmental coordination disorder (DCD) face motor difficulties in many activities, interfering with their daily functioning.<sup>1, 2</sup> The impact of the disorder becomes evident in activities of daily living (ADL), such as getting dressed, using cutlery, riding a bike, and bathroom activities; handwriting and doing craftwork; ball skills, running, and all sorts of play.<sup>1, 3-9</sup> DCD has a prevalence rate of 5-6% in school-aged children.<sup>1</sup> It is a heterogeneous disorder, with individual children facing different problems, in different motor areas, and to a different extent.<sup>5, 6</sup> For example, the one child may specifically lack handwriting skills, whereas the other may have trouble with all kinds of motor activities, including frequently dropping things and bumping into objects and other children.<sup>5, 6</sup> The term “clumsy” often seems to be an adequate description when first seeing a child with DCD. The etiology of the disorder is until now unknown.<sup>1</sup> The impact of DCD is evident, however <sup>1, 3-9</sup>: children taking endless amounts of time to tie their shoelaces, eight-year-old children still struggling to write their own name legibly, or boys and girls being excluded from the playground games their peers are involved in.<sup>10-12</sup> As a consequence of their motor difficulties, children with DCD show restricted participation in ADL and face physical and psycho-social problems such as poor physical fitness, low self-esteem, and social exclusion.<sup>3, 6, 8, 13-15</sup>

In order to limit the consequences of the disorder for children with DCD, new interventions were developed, which are directed at the improvement of functional motor skills, and these were shown to be successful.<sup>16-20</sup> Further, an international consensus-based guideline was recently developed on the operationalization of the diagnostic criteria for DCD, recommending standardized and objective assessment of ADL.<sup>1, 4</sup> These efforts in both intervention and diagnosis highlight the importance of ADL difficulties in children with DCD. Insight into the specific ADL difficulties of individual children with DCD was lacking, however, despite being essential for diagnosis and the planning of intervention.<sup>4, 14, 21</sup> The aim of this thesis was to develop ADL assessment, suitable for five to eight-year-old children with DCD: both a validated clinical test and a parental questionnaire that comprise a comprehensive range of essential ADL.

## BACKGROUND

Owing to the unknown etiology of DCD, various names have been used to describe “motor difficulties” in children over the years. As early as 1900, different levels of motor ability were reported, e.g. varying from very clever to very awkward.<sup>22</sup> Clumsiness in

children was first reported in 1937, with their “abnormal clumsiness” suggested to be due to “a failure in development of normal skills”.<sup>23</sup> In line with the supposed etiology of the disorder, the terminology varied from “developmental apraxia” and “dyspraxia” to “sensory- and perceptual-motor dysfunction,” “motor learning disorder,” or, less specific, “the clumsy child syndrome,” or “minimal brain damage”.<sup>5, 24, 25</sup> These labels were used both interchangeably, or to describe different sub-types suggested to underlie the disorder.<sup>24, 26</sup>

The idea of a “general cerebral dysfunction” or “minor neurological dysfunction” may relate to the many comorbidities found in children with DCD, such as Attention Deficit Hyperactivity Disorder, language problems, and reading difficulties, and to the fact that DCD is more common in preterm and low-birth-weight children.<sup>1, 27</sup> However, “evidence suggests that it is a unique and separate neurodevelopmental disorder”.<sup>4</sup> Further, children’s motor difficulties are preferably considered on their own, to facilitate diagnosis and intervention.<sup>24</sup>

In 1994, international consensus was reached to use the label “developmental coordination disorder”.<sup>28</sup> This terminology refers to the neurodevelopmental nature of the disorder and links to the coordination difficulties rather than to the “clumsy” child.<sup>5</sup> The label DCD has indeed been used in the vast majority of studies since.<sup>29</sup>

## Diagnosis

As there is no clear medical condition underlying the disorder, a golden standard to diagnose DCD is lacking.<sup>1, 30</sup> Clear diagnostic criteria are present, however (see Table 1). Both inclusive criteria (A and B) mention difficulties in ADL to be a key-feature of the disorder, i.e. children’s motor skills are below that expected, resulting in poor execution of several ADL, which interferes with ADL and academic achievement.<sup>1, 4-8, 14, 31</sup>

### *Assessment*

International consensus was reached on the operationalization of the diagnostic criteria for DCD (see Table 1).<sup>1, 4, 31</sup> It is recommended in this guideline that both inclusive criteria (A and B) should be assessed with a valid and reliable instrument, i.e. with a standardized clinical test.<sup>1, 4, 31</sup>

For assessment of Criterion A, the Movement Assessment Battery for Children-2 (MABC2) is the most commonly used instrument.<sup>4, 32</sup> This instrument addresses children’s motor abilities in eight different “tasks,” in the fields of manual dexterity, aiming & catching, and balance. According to the recently developed guideline, the MABC2 provides excellent operationalization of diagnostic criterion A (see Table 1).<sup>1, 4, 7, 31</sup>

For assessment of criterion B, questionnaires are currently used such as the MABC2-Checklist and Developmental Coordination Disorder Questionnaire (DCDQ; see

Table 1).<sup>1, 4, 32, 33</sup> A standardized and objective clinical test for assessment of Criterion B was concluded to be lacking.<sup>4</sup>

### *Directions for a next step*

Despite being needed for the operationalization of the diagnostic criteria for DCD, a standardized and objective clinical test for assessment of Criterion B is lacking.<sup>4</sup> The need for ADL assessment was confirmed in a recent systematic review, showing that little is known about the specific ADL difficulties in children with DCD.<sup>14</sup>

**Table 1.** Diagnostic criteria for developmental coordination disorder and their operationalization.

	Diagnostic criteria (2000) <sup>31</sup>	Operationalization <sup>4</sup>	Diagnostic criteria (2013) <sup>1</sup>
A	Performance in daily activities that requires motor coordination is substantially below that expected given the person's chronological age and measured intelligence. This may be manifested by marked delays in achieving motor milestones (e.g. walking, crawling, sitting), dropping things, 'clumsiness', poor performance in sports, or poor handwriting	A score equal to or lower than the 16 <sup>th</sup> percentile on the MABC2 <sup>32</sup>	The acquisition and execution of coordinated motor skills is substantially below that expected given the individual's chronological age and opportunity of skill learning and use. Difficulties are manifested as clumsiness (e.g. dropping or bumping into objects) as well as slowness and inaccuracy of performance of motor skills (e.g. catching an object, using scissors or cutlery, handwriting, riding a bike, or participating in sports)
B	The disturbance in criterion A significantly interferes with academic achievement or activities of daily living	An indication for problems with ADL (currently operationalized as a score equal to or lower than the 15 <sup>th</sup> percentile on the DCDQ <sup>33</sup> or MABC2-Checklist <sup>32</sup> )	The motor skills deficit in Criterion A significantly interferes with activities of daily living appropriate to chronological age (e.g. self-care and self-maintenance) and impacts academic/school productivity, prevocational and vocational activities, leisure, and play
C	The disturbance is not due to a general medical condition (e.g. cerebral palsy, hemiplegia, or muscular dystrophy) and does not meet the criteria for Pervasive Developmental Disorder	The motor disturbance is not due to a general medical condition (e.g., cerebral palsy, hemiplegia, or muscular dystrophy or pervasive developmental disorder) according to the results of a pediatric neurological examination	Onset of symptoms is in the early developmental period
D	If mental retardation is present, the motor difficulties are in excess of those usually associated with it		The motor skills deficits are not better explained by intellectual disability (intellectual developmental disorder) or visual impairment and are not attributable to a neurological condition affecting movement (e.g. cerebral palsy, muscular dystrophy, degenerative disorder)

## **Intervention**

In line with the variation in assumed etiology of the disorder, focus of intervention for children with DCD has shifted over the years.<sup>5, 24</sup> In the second half of the 20<sup>th</sup> century for example, perceptual-motor programs and the sensory-integration approach were broadly used.<sup>5, 24, 34</sup> More recently, in addition to these process-oriented approaches, task-oriented approaches were developed, such as Neuromotor Task Training (NTT) and Cognitive Orientation to daily Occupational Performance (CO-OP).<sup>16,17,19,35</sup> These modern interventions are directed at improvement of functional motor skills that children need in daily life. Specified instructions and feedback are used to facilitate transfer from practice to daily functioning. These task-oriented interventions have proven successful to limit the daily consequences for children with DCD.<sup>18</sup>

### *Directions for a next step*

The effectiveness of these interventions may be further improved by standardized and objective assessment of ADL, as insight into the ADL difficulties of the individual child with DCD may guide clinicians in planning tailored intervention. In addition, assessment of ADL would enable evaluation of these treatment methods as it directly relates to the functional motor skills that are practiced during intervention.<sup>21</sup>

## **THE NEXT STEP**

In order to add to the operationalization of the diagnostic criteria for DCD as well as to support intervention of children with DCD, eventually aimed to improve their daily functioning, the next step would be to develop ADL assessment for children with DCD that reveals children's difficulties in daily functioning.

## **THEORETICAL FRAMEWORK**

### **Activities of Daily Living**

In this thesis, ADL are defined as “motor-based activities with a functional or meaningful goal that are performed on a daily basis.” Examples are pouring a drink, handwriting, and riding a bike. Activities that are not considered ADL are for example standing on one leg or a transfer from sit to stand. Although both may occur every day, these latter activities are not functional or meaningful activities in themselves. In the uniform terminology for occupational therapy, ADL are described as “purposeful tasks necessary for self-maintenance”.<sup>36</sup> This thesis refers to the three domains of ADL that are widely recognized

to be relevant for children: “self-care and self-maintenance,” “productivity and schoolwork,” and “leisure and play”.<sup>5, 7, 8, 36-39</sup>

The definition of ADL used in this thesis relates to the conceptual model of the International Classification of Functioning, Disability and Health (ICF), which is the universal framework for health-related conditions (see Figure 1).<sup>2</sup> In this model, ADL form part of the components “activities” and “participation,” in which *activities* are described as the “execution of a task or action, representing the individuals’ perspective or functioning,” and *participation* as a person’s “involvement in a life situation”.<sup>2</sup>

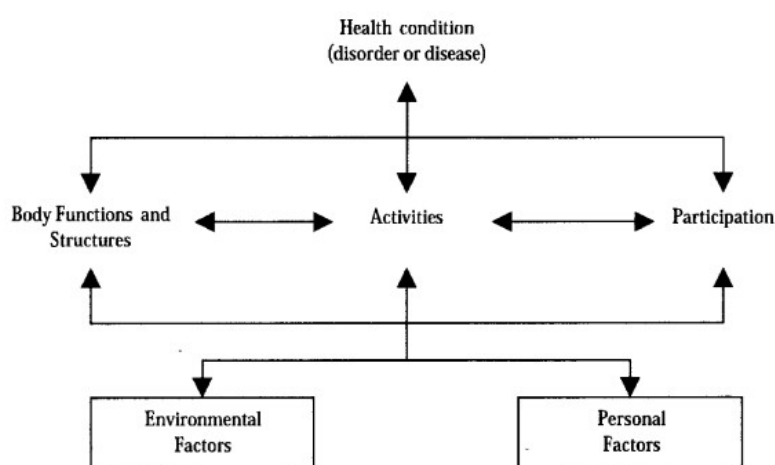


Figure 1. Model of the International Classification of Functioning, Disability and Health.<sup>2</sup>

ADL may be addressed at both activity and participation level. At activity level, both a clinical test or a parental or teacher questionnaire may be used to address how well children perform tasks. Assessment with a clinical test may provide insight into *capacity*, i.e. what children “can do” in a standardized environment, whereas *performance* may be addressed with a questionnaire, to reflect what children “do” in daily life.<sup>2, 40</sup> At participation level, questionnaires are used to address whether children participate in certain ADL, i.e. how often they are involved in these ADL during daily life.

### Specifications for assessment

Comprehensive and multi-level assessment of ADL is needed to fully reflect the limitations in daily functioning in children with DCD.<sup>21, 34, 41</sup> Focus of this thesis is on five to eight-year-old children, as DCD is often recognized around school-age.<sup>5</sup> Further specifications are listed below.

The first considers the heterogeneity of the disorder.<sup>5, 6</sup> In order to cover the wide range of variation in children’s everyday functioning, ADL assessment should (a) comprise the broad range of ADL that children with DCD face trouble with according to

the literature, and (b) cover the three domains of “self-care and self-maintenance,” “productivity and schoolwork,” and “leisure and play.”

Second, both *capacity* and *performance* in ADL need to be addressed. What a child is capable of (capacity) may differ from what a child does (performance), and both a clinical test and a questionnaire reflect only to some extent actual daily functioning.<sup>2, 40</sup> Clinical assessment of ADL should be provided with clear instructions, standardized materials, and norm scores, to obtain objective and comparable results. For children’s performance, parental questionnaires are a valuable source of information as these provide a long-term perspective instead of results of specific moments of testing.<sup>42</sup>

Finally, according to the diagnostic criteria for DCD, having the disorder does not only imply poor [capacity or] performance in ADL, but also delays in learning of ADL and less participation in ADL compared to peers.<sup>1</sup> Assessment of delays in learning of ADL, i.e. whether children take or took longer to learn specific ADL than their age peers, is considered of worth to support early recognition and to prevent performance difficulties. Insight into children’s participation in ADL, i.e. how often children perform specific ADL, is also considered valuable. Participation is an important outcome of health,<sup>2</sup> and stimulation of participation may prevent or limit secondary consequences such as social exclusion.<sup>6, 15, 43</sup> Both learning and participation can be addressed with a questionnaire.

Concluding, in order to optimally evaluate the difficulties that children with DCD are faced with during daily life, both a clinical test and a questionnaire are needed to assess ADL. A standardized and objective instrument would enable clinical assessment of children’s capacity in ADL, as recommended for the operationalization of diagnostic criterion B. In addition, a parental questionnaire would enable parallel assessment of children’s ADL performance, learning, and participation. In order to best reflect children’s daily functioning, both should cover a comprehensive range of ADL.

## AIM AND OUTLINE OF THIS THESIS

The main aim of this thesis was the development of both a clinical test, the DCDDaily, and a parental questionnaire, the DCDDaily-Q, in order to enable comprehensive ADL assessment in five to eight-year-old children with or suspected of having DCD.

*Chapter 2* of this thesis provides a systematic review of instruments with potential for standardized and objective assessment of children’s capacity in ADL, suitable for children with DCD. Once instruments were included for review according to specified criteria, test characteristics such as test goal, clinical use, and range of ADL covered per domain were evaluated in order to reflect the applicability of these instruments for ADL assessment in children with DCD. *Chapter 3* describes the DCDDaily that was developed



## CHAPTER I

to provide standardized and objective clinical assessment of children's capacity in a comprehensive range of ADL. This chapter describes (a) the development of the instrument, based on thorough review of the literature and expert consensus, and (b) the investigation of the usability (assessment time and feasibility), reliability (internal consistency and repeatability), and validity (concurrent and discriminant validity) of the DCDDaily. The DCDDaily-Q, a parental questionnaire developed to enable parallel assessment of children's ADL performance, learning, and participation, is described in *Chapters 4* and *5*. In *Chapter 4*, the psychometric properties of this questionnaire were investigated for children's performance of ADL, i.e. internal consistency, concurrent validity, discriminant validity, and ability to predict the presence or absence of DCD. In *Chapter 5*, differences in ADL performance, learning, and participation were investigated between children with DCD and their typically developing peers. Aim of this chapter was to specify the difficulties that children with DCD are faced with during daily life. Furthermore, predictive relations between ADL performance, learning, and participation were explored, aimed to add to our understanding of the disorder. Finally, *Chapter 6* provides a summary and discussion on the work presented in this thesis. Directions for future research are suggested, and implications of the DCDDaily and DCDDaily-Q for professionals and children with DCD are discussed.

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CHILDREN WITH DEVELOPMENTAL COORDINATION DISORDER (DCD) FACE EVIDENT MOTOR DIFFICULTIES IN ACTIVITIES OF DAILY LIVING (ADL). ASSESSMENT OF THEIR CAPACITY IN ADL IS ESSENTIAL FOR DIAGNOSIS AND INTERVENTION, IN ORDER TO LIMIT THE DAILY CONSEQUENCES OF THE DISORDER. THE AIM OF THIS STUDY WAS TO PROVIDE A SYSTEMATIC REVIEW OF INSTRUMENTS WITH POTENTIAL FOR STANDARDIZED AND OBJECTIVE ASSESSMENT OF CHILDREN'S CAPACITY IN ADL, SUITED FOR CHILDREN WITH DCD. AS A FIRST STEP, DATABASES OF MEDLINE, EMBASE, CINAHL, AND PSYCINFO WERE SEARCHED TO IDENTIFY STUDIES THAT DESCRIBED INSTRUMENTS WITH POTENTIAL FOR ASSESSMENT OF CAPACITY IN ADL, IN CHILDREN WITH MOTOR DIFFICULTIES. SECOND, INSTRUMENTS WERE INCLUDED FOR REVIEW WHEN TWO INDEPENDENT REVIEWERS AGREED THAT THE INSTRUMENTS (A) ARE STANDARDIZED AND OBJECTIVE; (B) ASSESS AT ACTIVITY LEVEL AND COMPRISE ITEMS THAT REFLECT ADL; AND (C) ARE APPLICABLE TO SCHOOL-AGED CHILDREN THAT CAN MOVE INDEPENDENTLY. OUT OF 1507 PUBLICATIONS, 66 PUBLICATIONS WERE SELECTED, DESCRIBING 39 INSTRUMENTS. SEVEN OF THESE INSTRUMENTS WERE FOUND TO FULFILL THE CRITERIA AND WERE INCLUDED FOR REVIEW: THE BRUININKS-OSERETSKY TEST OF MOTOR PERFORMANCE-2 (BOT2); THE DO-EAT (DO-EAT); THE MOVEMENT ASSESSMENT BATTERY FOR CHILDREN-2 (MABC2); THE SCHOOL-ASSESSMENT OF MOTOR AND PROCESS SKILLS (SCHOOLAMPS); THE TUFFTS ASSESSMENT OF MOTOR PERFORMANCE (TAMP); THE TEST OF GROSS MOTOR DEVELOPMENT (TGMD); AND THE FUNCTIONAL INDEPENDENCE MEASURE FOR CHILDREN (WEEFIM). AS A THIRD STEP, FOR THE INCLUDED INSTRUMENTS, SUITABILITY FOR CHILDREN WITH DCD WAS DISCUSSED BASED ON THE ADL COMPRISED, ECOLOGICAL VALIDITY, AND OTHER PSYCHOMETRIC PROPERTIES. IT WAS CONCLUDED THAT CURRENT INSTRUMENTS DO NOT PROVIDE COMPREHENSIVE AND ECOLOGICALLY VALID ASSESSMENT OF CAPACITY IN ADL AS REQUIRED FOR CHILDREN WITH DCD.

CHAPTER 2. INSTRUMENTS FOR ADL ASSESSMENT IN CHILDREN WITH DCD